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ABSTRACT

This compilation of materials offers an overview paper and an annotated bibliography on self-determination. The overview paper on self-advocacy for individuals with developmental disabilities, authored by Michael Kennedy and Patricia Killius, presents a definition of self-advocacy, notes that poor communication skills should not prevent an individual from participating in community living, emphasizes that self-advocacy means having choices and having a say about services, and presents guidelines for starting a self-advocacy group. An annotated bibliography on self-determination describes 13 articles, journals, books, and other resources. (JDD)

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MATERIALS ON SELF-DETERMINATION

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SELF-ADVOCACY: SPEAKING FOR YOURSELF

by Michael Kennedy & Patricia Killius
(Recorded and Edited
by Deborah Olson, 1986)

As self-advocacy coordinators at the Center on Human Policy, we speak to professionals, parents, and the general public to tell them that disabled people have rights. We want them to know that we can make decisions and speak out for ourselves.

We also teach people with developmental disabilities and mental retardation that they have the right to self-determination and to live as independently as is possible for them. Both of us lived in institutions for years, so we know what it's like for others.

One way we do this is to facilitate self-advocacy groups. In these groups, people like ourselves learn to speak out for themselves. People with all kinds of disabilities participate in the groups. Some of them still live in the institution, but most live in group homes, supportive apartments, with families and even independently.

In July, 1985, we held the first New York State conference of self-advocacy for people with developmental disabilities. The purpose was to give people with developmental disabilities the chance to speak out about their rights and the things they want to see changed. We also wanted professionals to see that we have a voice of our own. We want the same rights as everyone else. Nothing more, nothing less.

Definition

Self-advocacy means people with developmental disabilities speaking up and speaking out for their rights. For people who can't speak, it may mean having someone interpret what you want to say. People with developmental disabilities should have the right to speak up and teach other people about their rights. We won't always have someone to look out for us.

People need to listen to what we want even though they might not want to. Speaking out can be taking a risk. Sometimes you're afraid a staff person might say no.

Some People Can't Speak for Themselves

Some people can't talk or communicate easily with others. Other people may be really shy or uncomfortable talking. This shouldn't mean they can't be part of everyday life. Someone with a severe disability can still live a good life in the community even though they can't express themselves very well or communicate their wants clearly. They may need a friend who can speak for them. The best spokesperson for someone who can't speak may be another person with a disability who can speak, maybe a friend of that person. Another disabled person knows where that person is coming from; they've had similar experiences. Professionals may say they understand, but in reality they haven't lived as we have and haven't had the same experience.

> MIKE: Ted and I were in the same institution together many years ago. When we met again recently I could still understand him, even though he has really difficult speech and it's hard for other people to understand him.
>
> PAT: Even for someone who can't speak at all, another person who's disabled is still a good spokesperson just because you know what it is like to be a consumer or to live in an institution.

Self-Advocacy is About Having Choices

Living in the institution you don't have the freedom to make choices. You are told what to do, for example, when to eat, when to sleep and when to get ready for work.

You have no choice about going places when the whole unit is going someplace. You can't go out on your own.

> MIKE: Now I can do things with other people or by myself if that's what I want. At least I have a choice.

Self-advocacy, or speaking for yourself, is a big part of living in the community. People with disabilities who live in the community should have the right to make their own decisions, just like anyone else. For example, we should have the choice of who we want to work for us. In our apartment, the director will interview a person who wants to work with us. Then she will bring them to the apartment and have us interview the person. We ask things like, "Have you ever worked with disabled people before?" "What kind

of recreational things do you like to do?" We ask this so that we can get a good idea of what they like to do and if we like the same thing. We also ask how they feel about transferring someone from one chair to another. We ask to get an idea of how they feel about being with us.

After these questions, the person asks questions of us. We'll give them answers about where we work and what we do.

The following day we get together with the director and talk about that person. She takes our ideas to the board of the agency and the board usually approves who we recommend for hiring.

The choices you should have are choosing your own friends and having your friends come to see you, going to the church of your choice when you want to go, deciding whether to have a real job instead of working in a sheltered workshop or activity center, and lots of other choices. Sometimes people with developmental disabilities need help making choices, or even knowing what their options are. Parents, staff, and friends can help people learn about choosing, if they pay attention to the person.

Self-Advocacy Means Having a Say About Your Services

People with developmental disabilities can and should have an impact on services by participating in agency boards and councils. It's important that we share our ideas because we use some of the services. Many of us have been getting services from agencies all our lives. We know that some services are good because they try to meet our individual needs. We also recognize that some services are bad because they don't integrate people in the community and they don't provide programs to help us become more independent. We can tell agencies what kind of things we need to live and grow in the community. But it's not enough to have just one consumer on a board. If there are several with different disabilities or different experiences, providers will know more about your needs.

When we first got our self-advocacy jobs a lot of agencies asked us to be on their boards. They didn't seem to be aware of other people with disabilities who could also speak on their programs.

PAT: The same two consumers shouldn't be on all the boards in the community, because they're going to get tired of hearing from us. There are other consumers who would learn a lot from the experience and also contribute to the board.

People with disabilities might need special supports to be on a board. For example we might need aides to help us get to the meeting, to help us with personal needs, for writing and reading, for speaking for someone who can't speak or interpreting for someone who can't hear. It's important to have this support so that we can participate on the board. Without this support we're just a token.

Learning About Self-Advocacy

All disabled people have the right to learn to speak for themselves. It's important because there will be a day when our parents won't be able to speak for us. Disabled people can teach each other how to speak for themselves. Role-playing a variety of problems or situations is a good way to learn self-advocacy.

There's more strength in forming a group. One individual speaking out is easily over-looked. If you have a group of people who want the same thing, you have a better chance of people listening.

This is what we did in Syracuse. We drew up a list of friends and other people we knew. We told them about self-advocacy and asked them if they wanted to become involved. That's how we got started.

We brainstormed some issues and talked about issues at every meeting. For example, we talked about transportation problems and education.

To teach ourselves about our rights we used a tool called Rights Now! It contains cassettes, pictures and a slide show about different people in situations learning about self-advocacy. For instance, finding meaningful work instead of sheltered employment, finding time to be alone with your friends, or working out compromises with the people you live with. Rights Now! is not available any more, but you might be able to get it from your state's Protection and Advocacy agency.

Ways to Start a Group

We started our groups through the College for Living, but not everybody has to do it the same way. There are many ways to start a group.

First, you have to find a good place to meet. It should be easy for everyone to get to it. Then you have to make a list of people to be a part of the group. It's OK to start small. You have to let people know about the meeting either by calling them or seeing them at work or where you live. You have to agree on a meeting date and time that would be good for everybody.

When you have your first meeting, you have to be sure that everyone feels comfortable. You should have people introduce themselves and maybe say why they wanted to learn about self-advocacy. You may have to explain about self-advocacy first. If you decide to use the Rights Now! material, you'll have to tell them about the cassettes and pictures. Or you could show a film, like the People First film, or a slide show, like Our Voice Is New (which we helped produce) about self-advocacy. After the film or slides you can talk about some of the issues, like speaking out, having someone speak for you if you can't speak well, or what it feels like to be labeled mentally retarded.

We and the people in our group think that it is good to form a group because:

1. People aren't always going to be around to make decisions for you, you have to learn to make your own decisions.

2. You can learn about each other, everyone has different needs.

3. You can work together for new opportunities for people with disabilities.

4. You can learn about your rights as a citizen.

5. You can help other people who can't speak.

6. You can have fun by meeting other people.

By speaking for yourself you make other people--group home staff, government officials, and the general public, see that you are a person just like them, not a "disability." Self-advocacy is a part of living in the community. Without it we might as well be shoved back into the institution.

ANNOTATED BIBLIOGRAPHY ON SELF-DETERMINATION

The fundamental right of speaking for oneself has long been denied to people with disabilities, who have usually had decisions made for them about every detail of their lives. They were, in other words, taught dependence. In the past twenty years, however, people with disabilities have organized movements (e.g., the self-advocacy movement, the independent living movement, the "psychiatric survivors" movement) that prove that that people upon whom dependence was imposed can and must speak for themselves and determine their own futures. An exciting recent development has been that the leaders and members of the different movements are talking to and including each other, recognizing the commonalities between them and the issues they face.

The materials in this section emphasize the self-advocacy movement, which was organized by and for people with developmental disabilities, but the section includes materials produced by other groups as well.

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One of the most important features of the last book is that is highlights particular skills in areas that facilitate group dynamics like communication, listening, being assertive, etc.

A particularly strong feature of this set of books is the simple language that is used to communicate its intent. Another strength is that it emphasizes that it is alright to ask people for help if one needs it, and offers a section on how to choose an advisor for the group who will not lead but empower. Each section in each book has a number of exercises and summaries of the important points. Also provided are a list of resources that could be used to complement the texts. In terms of a book that offers good suggestions, without being didactic, this book scores high.

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TITLE: The last civil rights movement: Disabled People's International

AUTHOR: Driedger, D.

PUBLICATION INFORMATION: 1989

St. Martin's Press, Inc.
175 Fifth Avenue
New York, NY 10010

The disability movement appears to be the last of the social movements of the 20th century. At least this is the claim made by Driedger in this book. Based on interviews, reports, letters and documents by those involved in Disabled People's International, Driedger argues that people with disabilities have a distinctive history that cannot be in accordance with viewing them as clients, patients or deviants dealt with by professionals.

Driedger articulates what the Disabled People's International (DPI) defines as a disability: the inability of the social environment in the community to accommodate to the needs of people who have limitations. She also points out that historically people with disabilities had little to say in any of the policies that are affecting their lives. In light of these philosophies, DPI was born as an organization "of" handicapped individuals rather than an organization "for" handicapped individuals. The book goes on to describe the history of DPI, the early years of struggle to get to be a group, and its goals and objectives.

One of the particularly redeeming features of this book is that it frankly voices the difficulties faced by an organization that claims to represent people with disabilities internationally. It lists the power politics among the "old boys" in the group, the elitism that often develops in leadership and the omission of people who are not powerful and who may have a voice in decision making. Of particular importance was the issue of people with disabilities in developing countries whose extreme poverty and lack of resources often prevented them from participating in DPI sponsored events. Also mentioned are difficulties, political and otherwise, that affect an organization of international dimensions.

This book has inherent value in that it attempts a realistic portrayal of a self-advocacy organization with its warts and all. It also very effectively places the field of disability in the context of a social movement that can effect social change in the field of today.

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TITLE: How to be an effective board member: Manual for self-advocates, manual for facilitators

AUTHOR: Eddy, B. A., Cohen, G. J., & Rinck, C.

PUBLICATION INFORMATION: 1989, December

University of Missouri-Kansas City
Institute for Human Development
2220 Holmes, Room 321
Kansas City, MO 64108

These two manuals are valuable additions to the sparse literature on how self-advocates can be effective as board members. The materials in these two manuals can be used to train self-advocates, or can be used directly by self-advocates who can read. The manual for self-advocates contains many drawings and pictures illustrating the text, which describes meetings, rules, board members' rights and duties (e.g. the right to ask for clarification, the right to voice an opinion, the duty to maintain order and sometimes confidentiality, etc.), and presents samples of board orientation materials. While the examples used are based on Kansas City or Missouri services and boards, the manuals would be useful to people in other states.

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TITLE: We are People First: Our handicaps are secondary

AUTHOR: Edwards, J. P.

PUBLICATION INFORMATION: 1982

Ednick, Inc.
Box 3612
Portland, OR 97208

What happens when a group of former institution residents who are tired of being misrepresented and devalued decided to do something about this? They form a self-advocacy group: People First. We are People First describes the origin of the movement and its philosophy.

"People First" was started on January 8, 1974. Since then it has grown into a movement that has effectively articulated the needs of its members. The organization thus affords a chance to members to practice self-advocacy and self-assertion skills. A section of the book describes the early years, the difficulties, the conventions that were organized and the slow but steady growth of the organization into one of international dimensions. Some of the themes deemed important were the appreciation of help, the need and value for friends, pride in one's accomplishments

and the negative effects of labeling. A section also describes how the members consider the role of the helper, a theme that today's self-advocates and professionals are still arguing about.

This book makes fascinating reading. It describes how individuals who were formerly dismissed as nobodies and interred in institutions have managed to fight back and articulate a strong message. Behind the obscuring handicap, is a person with dynamism and a vision to effect change.

TITLE: The self-advocacy workbook

AUTHOR: Gardner, N. E. S.

PUBLICATION INFORMATION: 1980

Technical Assistance for Self-Advocacy Project
Kansas Center for Mental Retardation and
Human Development UAF
University of Kansas
Lawrence, KS 66045

This workbook provides a framework for learning about self-advocacy, organizing a group, and undertaking group action to deal with issues of common concern. The materials are specifically geared for use by a group. Each chapter attempts to focus on only one discrete aspect of organizing. Also, the structure of each presentation is the same throughout in order to minimize any problems the group might have with the management of their meetings.

TITLE: Changing ourselves and our community: Report of a leadership development process with a self-help group in mental health

AUTHOR: Lord, J.

PUBLICATION INFORMATION: 1983

Family and Friends
Mental Health/Waterloo Region
179 King Street, South
Waterloo, ON N2J 1P7
CANADA

and

Centre for Research and Education
in the Human Services
P.O. Box 3036, Station C
Kitchener, ON N2G 4R5
CANADA

That leadership is important in self-help groups is undeniable. This book is an attempt to document a process of change for any self-help group. The purpose of this report is to highlight the unique nature of the leadership development process with a self-help group in mental health and also to raise questions, outline resources and suggest ideas useful to other groups concerned about change. Care has been taken to highlight that this is a "specific process" from which a linkage to "general principles" and issues can be made.

The report deals with the purpose of having self-help groups and the importance of creating a context where members can gain skills and knowledge and expand people's awareness of values, strategies and processes which would be helpful in impacting on mental health issues. There are also sessions included where members can be involved in planning and implementation through role playing, sharing and examining individual needs. Further, this book explores the process of change in the group and in the community in terms of identifying issues that need resolving and utilizing problem solving skills to address these issues.

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TITLE: Speaking up and speaking out: An international self-advocacy movement

AUTHOR: People First of Washington, & Self-Advocacy Project, Rehabilitation Research and Training Center, University of Oregon

PUBLICATION INFORMATION: 1985

Ednick Communications
P.O. Box 3612
Portland, OR 97208

This self-advocacy booklet, perhaps the best resource on the various aspects of self-advocacy, is written for people with disabilities who have an interest in organizing or becoming part of a movement which advocates for their own rights and services. The roles of self-advocates and their advisors are clearly delineated in the booklet, but at the same time there is a recognition that each self-advocacy group will be unique.

The format of the booklet covers the planning and events of an international self-advocacy conference which was held by a group called People First (of Washington State). The conference participants share their experiences with words and pictures, providing a knowledge base to future self-advocates. Included throughout the volume are personal excerpts on people's thoughts and activities. The chapters cover basic issues such as describing self-advocacy, starting and supporting a local group, expectations about advisors, learning about self-advocacy, evaluating services, starting and supporting a state/province-wide organization, and other critical issues. An excellent resource.

TITLE: Self-determination

AUTHOR: Perske, R. (Ed.)

PUBLICATION INFORMATION: 1989

Institute on Community Integration
6 Pattee Hall, University of Minnesota
150 Pillsbury Drive, Southeast
Minneapolis, Minnesota 55455

This is a summary of the proceedings of a national conference on self-determination to which sixty people were invited by the Office of Special Education and Rehabilitative Services, U.S. Department of Education. Over half the planners have disabilities of one kind or another. This was a first: people with disabilities, parents, and close supporters being asked to draft specific recommendations for federal

officials regarding future directions for people with disabilities. This booklet presents their recommendations, some viewpoints of people at the meeting, and each of the keynote presentations.

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TITLE: How we lived and grew together: An interstate seminar on self-advocacy for persons with developmental disabilities

AUTHOR: Perske, R., & Williams, R.

PUBLICATION INFORMATION: 1984

InterServ
Clarence York, President
39 East 51st Street
New York, NY 10022

This is a report on the proceedings of a conference on self-advocacy for people with developmental disabilities. Some of the topics dealt with in this conference were the nature of meaningful work and participation in community activities, consumer empowerment and the effects of attitudes of the community and labelling by professionals of people with developmental disabilities. The booklet has several quotes from several government officials as well as from many program participants.

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TITLE: People with developmental disabilities speak out on quality of life: A statewide agenda for enhancing the quality of life of people with disabilities

AUTHOR: Vivona, V., & Kaplan, D.

PUBLICATION INFORMATION: 1990, March

World Institute on Disability
510 16th Street
Oakland, CA 94612
(415) 763-4100

This booklet provides a description of the World Institute on Disability's Quality of Life Project, a project that culminated in a series of conferences in which people with developmental disabilities discussed and made recommendations related to four areas: working, living, loving, and playing. Their recommendations are incorporated in the booklet, as are several appendices that would be helpful to those wishing to put on similar conferences.

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TITLE: We can speak for ourselves: Self-advocacy for mentally handicapped people

AUTHOR: Williams, P., & Shoultz, B.

PUBLICATION INFORMATION: 1984

Brookline Books
P.O. Box 1046
Cambridge, MA 02238
(617) 868-0360

This book tells the story of People First of Oregon, Project 2 of Nebraska, and similar efforts in England where participants have been building the skills necessary to take charge of their own lives. The book offers practical advice and support for parents, human service workers, and others interested in assisting self-advocacy for mentally handicapped people. It includes detailed descriptions of several organizations, lists teaching materials, and presents personal accounts by participants in self-advocacy groups both in the United States and in England. This book is also a valuable resource to sensitize the direct service worker, the administrator, and the public official to the importance of self-advocacy.